Socioeconomic Distress and Health Status: The Urban-rural Dichotomy of Services Utilization for People with Sickle Cell Disorder in North Carolina

By: Akhlaque Hague and Joseph Telfair

Haque, A. & Telfair, J. (2000) Socioeconomic Distress and Health Status: The Urban-Rural Dichotomy of Services Utilization for People with Sickle Cell Disorders in North Carolina. *Journal of Rural Health*, 16(1): 43-55. DOI:10.1111/j.1748-0361.2000.tb00435.x

Made available courtesy of Wiley-Blackwell: http://dx.doi.org/10.1111/j.1748-0361.2000.tb00435.x

Abstract:

Research on sickle cell disorder has not focused attention on the socioeconomic background and geographic distribution of people with the disease. This study examines 1,189 persons with sickle cell disorder in North Carolina during 1991 to 1995. Three indices were developed using clients' medical, psychosocial and socioeconomic characteristics for the purpose of analyzing the urban-rural difference in treatment for sickle cell disease. The study observed a wide disparity in these indices between urban and rural population groups. Also, differences were observed in the utilization of services and clients' health status. The findings suggest that utilization of services is directly related to socioeconomic condition facing clients and clinic distance front clients. They further suggest that people in rural areas who have high distress levels and are far from clinics have limited access to health care. The limited availability of medical and health care in rural areas, as well as other support systems calls for an increase in community based healthcare services. These findings should be of particular interest to the state level sickle cell disorder program in North Carolina and other areas with a large rural population. Enhanced support for all persons with sickle cell disorder in North Carolina, particularly those in rural areas, is critical.

Article:

Sickle cell disease (SCD) is an autosomal recessive disorder characterized by the production of abnormal hemoglobin and sickle shaped erythrocytes. The most common types of SCDs are hemoglobin SS (homozygous) disease hemoglobin SC disease and the beta thalassemia syndromes (the heterozygous types; Reid, et al., 1994). An estimated 72,000 Americans have been diagnosed with SCDs, most younger than 21 years of age (Reid, et al., 1994). In the United States, 95 percent of all SCD cases occur among blacks. It is the most common genetic disorder in this population group; the national incidence is 1 in every 400 live births (Rooks and Pack, 1983), in North Carolina the incidence is 1 in 475 (Whitworth, 1992). Approximately 1,900 people in North Carolina have an SCD, 45 percent of whom live in rural areas (Whitworth, 1993). SCDs affect men and women equally. Screening of newborns and electrophoresis testing are the primary identification mechanisms (Charache, et al., 1992). Individuals with an SCD are at risk for unexpected, intermittent and, at times, life-threatening complications (i.e., pain, priapism, joint necrosis, major organ damage; Serjeant, 1985); and psychosocial adjustment problems (Nash and Telfair, 1994; Thompson, et al, 1992; Abrams, et al., 1994; Barrett, et al., 1988; Gil, et al., 1992). Primary research addressing risk factors associated with SCDs has been predominantly in the biomedical (e.g., cell biology) and bioclinical (e.g., various treatment regimens) areas (Vichinsky, et al., 1983). This research has led to reduced morbidity and improved treatment outcomes and to the recognition of the need for comprehensive management strategies that address both biomedical and psychosocial issues (Vavasseur, 1987). In stark contrast to the major emphasis on biomedical and bioclinical research, studies of programmatic (aggregate) and client (individual) health service delivery are almost nonexistent. It is also unfortunate that very little is known about the lives of persons with SCDs and, more important, how geographic distribution affects their access to health care Thus, key questions of effectiveness,

availability access, differential outcomes and use of key programs and services that affect the quality of life for these individuals remain unanswered.

The purposes of this research were twofold. First, to explore the socioeconomic and health status disparity among urban and rural clients with SCDs in North Carolina; and, second, given the geographic distribution of clients and clinics (i.e., urban vs. rural), to answer the question. How does a client's socioeconomic status and health profile affect their ability to seek services at available clinics? In a nutshell, the research study underscores the socioeconomic condition of patients with SCDs in North Carolina and the impact of that condition on their utilization of services.

The paper is presented in four parts: (1) a discussion of the study background, data and methodology; (2) an analysis of the socioeconomic and self-reported medical backgrounds of people with SCDs categorized by geographic location; (3) the testing of a health services utilization model; and (4) a discussion of the implications for health care service delivery to persons with SCDs in North Carolina.

Sickle Cell Centers in North Carolina. The North Carolina Sickle Cell Disease Consortium (NCCSCD) provides much of the social, health and medical care for individuals with an SCD in North Carolina. NCCSCD has three administrative state employees and 10 regional educator/ counselors in four community centers (which provide social support services to clients) and five major tertiary medical centers (Duke University Medical Center, University of North Carolina [UNC] Hospitals, Bowman-Gray Medical School at Wake Forest University East Carolina University Medical Center and Carolinas Medical Center). The medical centers provide consultation and ongoing comprehensive medical and psychosocial management services for persons with an SCD. Only two centers, Duke and UNC, have adult programs, both are located in predominantly urban counties. Outreach activities to health and medical professionals in the community and outlying hospitals are limited to consultations and providing ongoing care for their clients. Between June 1992 and June 1993, 1,932 individuals with an SCD were served by program staff or by a contract medical center (Whitworth, 1993). NCCSCD data indicate that 86 percent of the visits to these centers were to seek care for an acute exacerbation or ongoing (not comprehensive) care only. A large number of the state's SCD clients live in rural counties and do not have regular access to clinicians, other multidisciplinary providers or to the state's major medical centers. The need for acute care is often episodic and may be dispensed by providers who may or may not be familiar with the contemporary aspects of SCDs.

As part of its comprehensive approach, NCCSCD (particularly the regional and community-based programs) links many of its service components with existing state and federal special health needs programs. However, most of these programs are for people younger than age 18 and their families (e.g., the North Carolina Child Service Coordination and Maternity Care Programs). Comparable programs for adults are few. Thus, independent of their involvement with the regional, community-based programs, or both, the unfortunate reality for adults with SCD is that when they leave any of the five pediatric SCD programs, they are on their own. This makes it difficult for them to seek out knowledgeable and willing practitioners to meet their medical and psychosocial needs. Anecdotal evidence suggests that lack of well-funded and coordinated programs for adults and children with chronic conditions has created differences in access to community and regional resources. However, there are no studies that begin to test whether or not these health services and condition specific problem differentials exist.

Evidence from North Carolina suggests that acute or wellness visits are taking place in the communities, if at all (Whitworth, 1993). It is well known that availability and distribution of health care resources in rural areas are scarce (Hicks, 1990; Brathwaite and Taylor, 1992; William, et al., 1994). It is suspected that because of distance and the socio-organizational (who the person sees upon entry into the system) characteristics of the service system, and the socioeconomic characteristics of the client, entrance into the system may not be "reachable, obtainable, or affordable" (Parker, 1974; Andersen, et al., 1983; Reif, et al., 1999). These disparities are believed to affect the rural client's actual use of services, service expectations and willingness to contact service providers to assist with a specific biopsychosocial need. The role of NCCSCD programs is to minimize the

known disparities of availability, access and utilization (realized access), but it is unclear what impact these programs have in reducing disparities for rural clients across service areas.

Data and Methodology

Data for this study came from the clinical database of the Duke/University of North Carolina Comprehensive Sidde Cell Center. The major purpose for creating the database was to record and track clinically useful information about all persons being served by any of the three medical centers participating in Sickle Cell Center activities and the center's community based-based affiliates.' The database contains self-reported demographic data, medical history, psychosocial information, objective physical examination results and laboratory and medical record data. Data were collected on 1,298 persons between 1991 and 1995 at a baseline visit and at subsequent yearly clinic visits. The database represents about 68 percent of the estimated number of people with sickle cell disease in North Carolina (Kinny, 1993). This study used cross-sectional data from intake interviews conducted on all patients.

ZIP codes of residence were available for 97.9 percent of the study population (n=1,189), all of whom resided in North Carolina. Because no reliable socioeconomic data were available from the intake forms or other sources, the socioeconomic status of individuals was measured indirectly by means of a community distress index (CDI) using 1990 U.S. census data. When individual-level data are not available, census data can be a valuable proxy for socioeconomic characteristics (Krieger, 1992; Roberts, 1997; Saul and Payne, 1999; Krieger and Gordon, 1999). Calculation of CDI is explained later in this section.

Data were categorized by urban and rural area. The U.S. census reports the number of persons considered as urban dwellers; for this study, ZIP codes were categorized as urban if 55 percent or more of its population were classified as urban, otherwise they were considered rural. Therefore, each client's ZIP code was categorized as either urban or rural. The SCD center (or hospital) locations were geographically coded (Figure 1) using a geographic information system-based ArcView software Utilization of services is expected to increase or decrease depending on the distance of the clinics from the clients. Clinic distance from a client was measured in straight lines using the ArcView program. An index was developed to reflect the socioeconomic condition of the areas where clients lived. Two additional indices were developed from clients who reported interference and medical background.

Community Distress Index. To identify the socioeconomic condition of an area (ZIP codes), an index was developed for each ZIP code in which clients lived. There are several different ways to develop such an index (see for example, Cohn, et al., 1994; Aldrich, et al., 1994); however, for our purposes, a simple index was developed using five variables commonly used to depict poor quality of life an area. Data were gathered from the 1990 U.S. census for the following variables: (1) percent of black population below poverty, (2) percent of blacks with not more than a 12th grade education, (3) percent of blacks not in the labor force, (4) percent of blacks unemployed and (5) per capita income of blacks.2 Given the distress indicators, the CDI can be defined as a method of identifying the socioeconomic condition of a geographic area using a combination of socioeconomic characteristics of the given population living in that area. Developing one single index from several different distress indicators gives a comprehensive profile of the socioeconomic condition of the area that may be used for comparison across areas of interest (Hague, 1998). Each variable was coded into groups that represented low, medium or high distress conditions (Table 1). By adding the five socioeconomic indices, CDI was calculated so that a higher CDI score would signify worse socioeconomic conditions of an area.

Figure 1. Map of Sickle Cell Clients in North Carolina

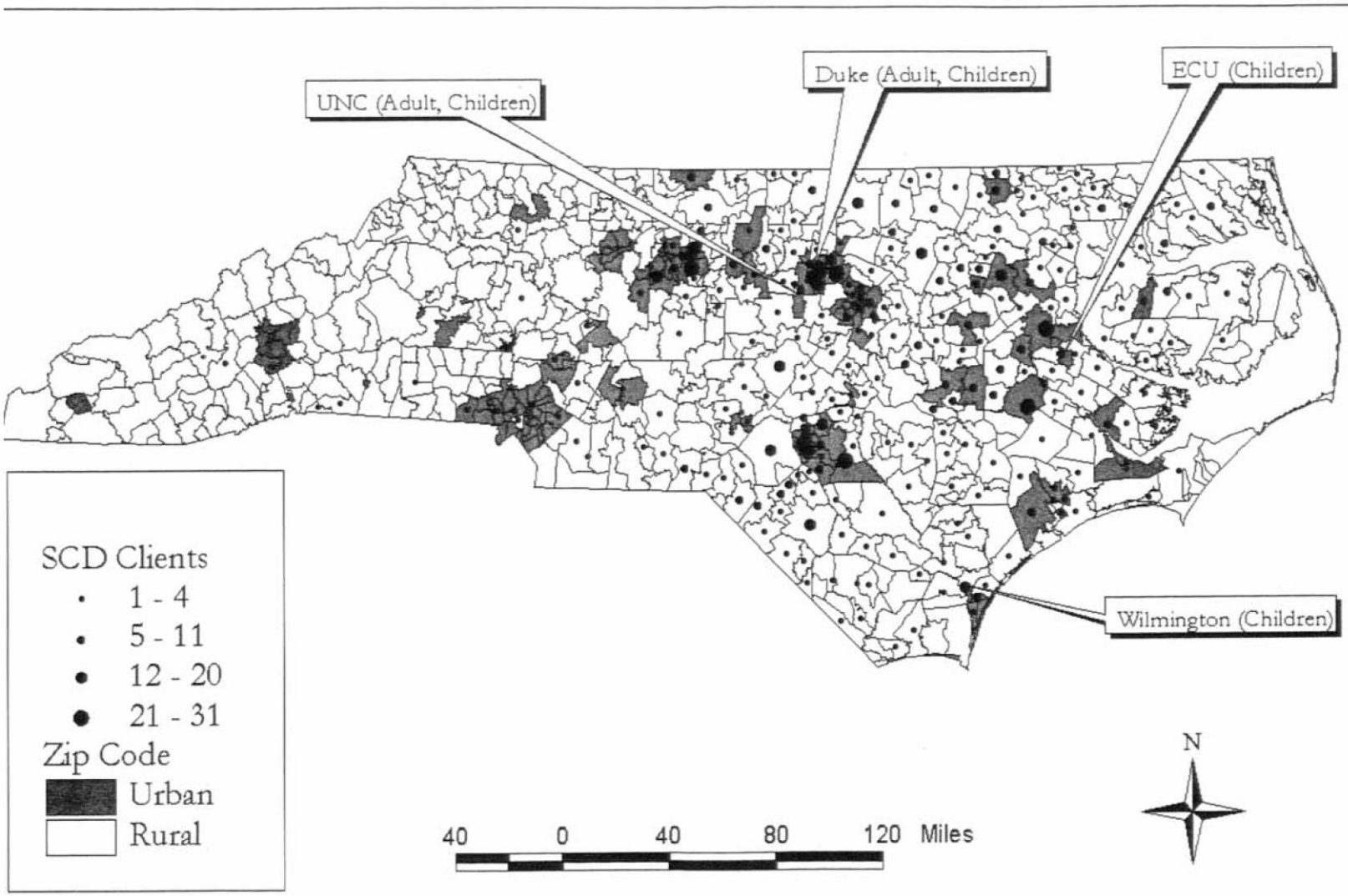

Table 1. Community Distress Index.

Variables	Definition	Code (n)
Income	Black per capita income	Very low = less than $4,000 (n = 4) Low = $4,001–$7,300 (n = 3) Medium = $7,301–$11,999 (n = 2) High = $12,000 and above (n = 1)
Education	Percentage of blacks not beyond high school education	High = 34% and above (n = 3) Medium = 26–33% (n = 2) Low = 0–25% (n = 1)
Poverty	Percentage of blacks below poverty	High = 31% and above (n = 4) Medium = 21–30% (n = 3) Low = 11–20% (n = 2) Very low = 10% and less (n = 1)
Unemployment	Percentage of blacks unemployed	High = 8% and above (n = 3) Medium = 4–7% (n = 2) Low = 0–3% (n = 1)
Not in labor force	Percentage of blacks not in labor force	High = 32% and above (n = 4) Medium = 21–31% (n = 3) Low = 11–20% (n = 2) Very low = 0–10% (n = 1)
Community index (1 through 5)	The higher the index, the worse socioeconomic condition is as explained by the five variables (range = 0–18)	High distress = 14 and above Medium distress = 9–13 Low distress = 0–8

Interference Index. To determine the extent to which SCD affects day-to-day sufferers, the National Sickle Cell Disease Self Help study's Psychosocial Interference Scale (PIS) was used (Nash, 1991; Kramer and Nash, 1992). The PIS consists of one total scale and four subscales that measure the extent to which a person perceives that SCD interferes with his or her day-to-day functioning, social and family relationships, school or work, sports and household activities. The PIS contains 12-item, 3-point Likert-type scale of formatted items (i.e., SCD interferes rarely, some or a lot equal scores of 0 to 2, respectively; Table 2). Based on Nash's work (1991), the reliability coefficient for the total scale was 0.9; for the present study the coefficient was 0.79. For this study, a weighted score was used based on the presence or absence (or nonrecording) of interference with a specific activity as well as the amount of interference as described. For analysis purposes scores were categorized as none (0), low (1 to 4), medium (5 to 12) and high (13 and higher). These latter modifications of Kramer and Nash's (1992) scoring patterns (presence or absence of interference) represent the clinically specific addition that was made by the staff of the Duke /UNC Comprehensive Sickle Cell Center for the purpose of including the scale to their overall clinic screening tool.

Medical Problem Index. As part of the baseline interview, self-reported information was collected on the presence and frequency of client's lifetime of medical problems (e.g., pain episodes), procedures (e.g., surgeries), infections (e.g., osteomyelitis) and conditions (e.g., aseptic necrosis of the hips). A medical problem index was developed to determine the extent to which these experiences affect the life of persons with SCD. Based on anecdotal and clinical information (Serjeant, 1985; Wagner, et al., 1989; Vichinsky [personal communication], 1992), the most common types of experiences (Table 2) were identified and coded as present (coded as 1) or not present (coded as 0) and weighted by count or frequency of occurrence (e.g, number of episodes of infections; Table 3).

Utilization of Services. Utilization of services is a ratio that describes for each ZIP code the total number of people who may be affected by SCD and the total number of clients who sought services from any of the available comprehensive clinics. In other words, utilization of services is the ratio of expected disease in a ZIP code by the actual number of clients seeking services in that ZIP code. Expected number of SCD clients in a ZIP code was calculated by multiplying the gene frequency of SCD (1 out of 475 or 0.0021) among blacks (Whitworth, 1992) with the number of blacks in the ZIP code. Figure 2 shows the geographic distribution of utilization of services as a percentage. A corresponding index was calculated by aggregating client information

from each ZIP code and calculating the mean for the indices. In addition, the corresponding distress level and interference and medical problem index was also calculated for each area.

Table 2. Interference Index.

Type of Interference	Population	Description of Code	
School attendance School performance Self-care Household activities Sports participation Socializing with friends Relationship with siblings Relation with other family members	Child	(1) Yes = 1; No = 0; No response = 0 (2) Amount of interference: Weighted Index (Child) = (1) × (2)	Rare = 1; Somewhat = 2; A lot = 3
Employment attendance Employment performance Self-care Household activities Socializing with friends Relationship with spouse/partner Relationship with children Relationship with other family members	Adult	(1) Yes = 1; No = 0, no response = 0 (2) Amount of interference: Weighted Index (Adult) = (1) × (2)	Rare = 1; Somewhat = 2; A lot = 3
Interference Index	Child	Interference index range: None = 0; Low = 1; Medium = 2; High = 3	
	Adult	Interference index range: None = 0; Medium = 2; High = 3	

Results

Client Population Profile: The Urban-Rural Continuum. A wide disparity in socioeconomic condition was observed between urban and rural clients (see Table 4). Fifty-four percent of the clients in the study population (648 cases) lived in urban areas, 46 percent (541 cases) lived in rural parts of North Carolina. The mean age for urban clients was 19 years, for rural clients it was 21. Clients in urban areas lived in relatively more prosperous neighborhoods; their average median family income was $35,500 compared with $33,700 for rural clients. Black per capita income for urban clients was almost $1,900 higher than for rural clients. Higher income for blacks in urban areas is reflected in a more educated black population in those areas compared with rural counterparts. In urban areas, 65 percent of blacks who were 25 years of age and older had a high school diploma compared with 43 percent in rural areas. Furthermore, the percentage of the black population living in poverty was 31 percent in rural areas compared with a much lower 24 percent in urban areas. The relative distress of rural clients is further exacerbated by a high percentage of the population not in the labor force – 29 percent in rural areas are unemployed compared with 22 percent in urban areas. The community distress index dearly reflects poorer socioeconomic status for rural clients – 43 percent of rural clients were in the high distress range compared with only 18 percent of urban clients (see Table 1 for range distribution). Seventeen percent of urban clients lived in low-distress areas, in contrast to only 4 percent of rural clients. Finally, for rural clients who attended child/adolescent clinics (Duke, UNC, Eastern Carolina University or Wilmington) the mean distance from a client's ZIP code to a clinic was 48 miles compared with 33 miles for urban dwellers. Adults had the option of attending one of the two adult clinics, either at Duke or UNC. Adult clients in rural areas had to travel an average of 76 miles compared, urban clients had to travel 55 miles. These statistics reveal a disparity in socioeconomic conditions between urban and rural SCD clients, highlighting the fact that rural clients are worse off or in more hardship than their urban counterparts.

Interference Index. Rural clients who have been living in relatively poor conditions reported that SCD interferes less with their daily activities than similar reports from urban counterparts. The analysis showed that 50 percent of rural clients reported that SCD has moderate to high levels of interference compared with 53 percent of urban clients. A low level of interference was reported by 49 percent of rural clients compared with 47 percent of urban clients. However, when interference was adjusted for type of interference (whether interference related to children or adults) and age (18 and younger or 18 and older), children in urban areas reported fewer interference than children in rural areas – 46 percent rural vs. 40 percent urban. For adult clients, differences in the level of interference between urban and rural clients was marginal. Therefore, urban-rural disparity in interference with daily activities may not be apparent for older clients; however, rural children are having a harder time coping with the disease than their urban counterparts.

Medical Problem Index. As expected, the study shows self-reported medical problems were higher for older clients. However, the urban-rural disparity remains for both age groups: urban clients reported more medical problems. Moderate to high medical problems were reported by 29 percent of urban clients compared with 25 percent of rural clients. For adults in urban areas, 78 percent reported moderate to high medical problems (of which 19 percent reported high levels). Self-reported medical problems in the moderate to high group for adults in rural areas were 71 percent (of which 15 percent reported high levels). These findings indicate that rural clients are having less physical (medical-related) problems compared with urban clients; however, children in rural areas report more interference in their daily activities. These relationships can be explained using bivariate correlation analysis.

Table 3. Medical Problem Index.

Event Group	Type of Event	Code Description
Problem	1. Acute chest syndrome/ pneumonia 2. Painful episode repairing	(1) Yes = 1, No or DK = 0 (2) Number of episodes: A = 1–5 episodes (n = 1) B = more than 5 episodes (n = 2) Problem index = [chest (1) × (2)] + [pain (1) × (2)]
Condition	1. Asceptic necrosis of hips 2. Asceptic necrosis of shoulders 3. Gallstones 4. Eye problems	Yes = 1; No or don't know = 0 Condition index = [hips + shoulders + gallstones + eye]
Infection	1. Osteomyelitis 1 2. Pyelonephritis 1	(1) Yes = 1; No or don't know = 0 (2) Number of episodes: A = 1 episode (n = 1) B = 2 or more episodes (n = 2) Infection index = [Os (1) × (2)] + [Py (1) × (2)]
Procedure	1. Surgery–cholecystectomy 2. Surgery–splenectomy	Yes = 1; No or DK = 0 Procedure index = [cho + spl]
Medical problem		Medical problem index = [Problem Index + Condition Index + Infection Index + Procedure Index]

Figure 2. Map of Utilization of Services in North Carolina.

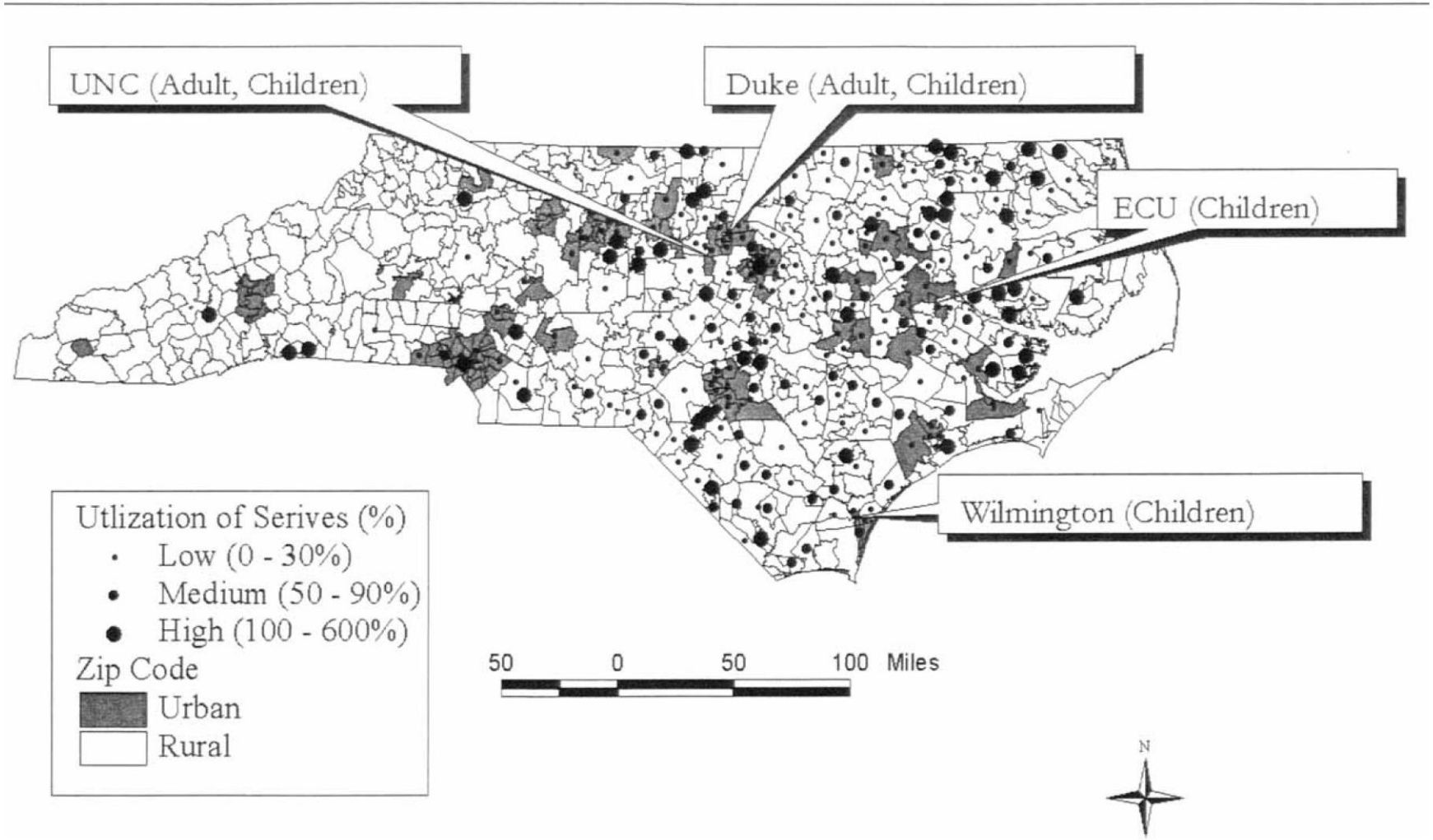

Table 4. Client Profile.

Variables	Urban (n = 648)		Rural (n = 541)	
	Mean	Standard Deviation	Mean	Standard Deviation
Percent age	19	14.8	21	15.4
Median income	$35,500	26,205	$33,700	2,859
Black per capita	$8,635	2,075	$6,771	1,803
Percent of blacks unemployed	4.3%	1.36	4.4%	1.7
Percent of blacks below poverty	24%	10.3	31%	10.3
Percent of blacks 25+ not beyond high school	18.7%	8.0	29.5%	6.1
Percent of black high school graduates	65%	24	43%	32
Percent of blacks not in the labor force	22%	7	29%	5.8
Clinic distance (child/adolescents; miles)	33	23	48	23
Clinic distance (adults; miles)	55	37	76	37
Community distress index	2.01	0.60	2.39	0.57
Interference index	0.88	1.01	0.88	0.95
Medical problem index	1.21	0.95	1.19	0.91

Source: 1990 U.S. Census (socioeconomic variables).

Bivariate Results. Bivariate correlation results reveal some important findings in addition to the clear differences in socioeconomic condition between urban and rural areas. The correlation matrix in Table 5 shows that CDI is positively associated with location (r=0.309; urban=1, rural =2), confirming that community distress is higher in rural areas. Furthermore, CDI has an inverse association with medical index and interference index (both indices weighted by age). This suggests that clients, who have a high CDI score are likely to have a lower medical index score and interference index score. This would imply that clients who have higher levels of medical problems and interference levels live in relatively prosperous neighborhoods (lower levels of CDI levels). This may be a mitigating factor; however, the correlation also highlights a disturbing finding that younger clients live in areas with a lower socioeconomic status or areas of high CDI scores (correlation between CDI and client age= —0.135). As expected, the weighted medical problem index is highly correlated with weighted interference index, which implies that clients with more medical problems tend to report more interference with daily activities.

Utilization of Services Model: Spatial Mismatch Analysis. As described in the methodology section, utilization of services is a ratio that describes for each ZIP code the total number of people who may be affected by the disease (1 out of 475 blacks in North Carolina) and the total number who sought services in any of the available comprehensive clinics. Therefore, utilization of services can be a useful measure in understanding the urban-rural dichotomy as well as how utilization of services may be affected by socioeconomic conditions, functional difficulties, severity of the disease and distance to clinics. We could hypothesize that as the distress level of clients increases, utilization of services will decline. Similarly, other factors could be directly related to clients' reluctance to seek services (such as severity of disease functional difficulties, distance to clinic), which could have a negative impact on utilization of services.

To find how utilization of services could be affected by a profile of patients with SCD, a model was developed with utilization of services as the dependent variable and other six variables as independent variables as follows:

$$UTS_1 = \alpha + \beta_1(DISTRESS_1) + \beta_2(INTF_1) + \beta_3(WMEDICAL_1) + \beta_4(DISTANCE_1) + \beta_5(LOCATION_1) + \beta_6(DISTANCE\_SES_1)$$

where UTS_1=utilization of services in ZIP code 1; $DISTRESS_1$=mean CDI of ZIP code 1; $INTF_1$=mean interference level of clients in ZIP code 1; $WMEDICAL_1$=weighted (by age) mean medical problem level of

clients in ZIP code 1; $DISTANCE_1$=mean clinic distance for clients in ZIP code 1; $LOCATION_1$=location of ZIP code 1 (urban= 1; rural=2); $DISTANCE\_SES_1$= (mean clinic distance from ZIP code 1) x (mean CDI of ZIP code 1).

Table 5. Correlation Coefficients for All Cases (n = 1,189).

	Correlation Coefficient				
Index	Community	Medical[1]	Interference[1]	Client Age	Urban/Rural
Community	—	−0.124*	−0.080*	−0.135*	0.309*
Medical[1]	−0.124*	—	0.616*	0.835*	−0.005
Interference[1]	−0.080*	0.616*	—	0.615*	−0.002
Client Age	−0.135*	0.835*	0.615*	—	0.045
Urban/Rural	0.309*	−0.005	0.002	0.045	—

1. Adjusted for age of client.
* Correlation is significant at the 0.01 level (2 tailed).

The regression results (Table 6) show that spatial location of clients clearly affects utilization of services. Utilization of services is predicted to be higher if more clients from rural areas seek services in clinics (B5= 0.377), so that clients from rural areas are more likely to effect utilization of services in SCD clinics than clients from urban areas. As predicted, the analysis further reveals that utilization of services is likely to decrease as clients' socioeconomic condition deteriorates.

Therefore, rural clients who are in worse socioeconomic condition than urban clients will likely use fewer services. Distance to a clinic could be a factor for their lower rates of utilization. Indeed, this was found to be the case, although it was not statistically significant. The direction of the relationship predicts that the farther a clinic is from its clients, the less rate of service utilization there is (134= -0.20). Therefore given that rural clients, especially adult clients, live farther from clinics, many of them may not be able to afford to seek services. When distance is interacted with distress an important finding has an intuitive appeal— utilization of services is likely to increase if the number of clients who live far from a clinic and are in a high distress group also increases (B6=0.466). From the point of view of SCD service providers, utilization of services will increase when they reach out to distant clients who are in a highly distressed condition. In a nutshell, clinics can increase their market share (utilization of services) by reaching out to clients in poor and distant neighborhoods of North Carolina who are in need of such services but who are unable seek them because of their socioeconomic condition. Finally, the weighted medical problem levels were inversely related to utilization of services. Although the relationship was not significant, the direction implies that clients who have relatively more physical problems tend to avoid seeking services, which, thereby negatively affects utilization of services. As seen from the low interference coefficient, interference level may not be as important as clients' socioeconomic condition or medical problems in influencing utilization of services. This may be the result of reporting. Interference for children is generally reported by parents or guardians. Such indirect reporting highlights the difficult reality of parental reporting of SCD interference and reporting in general.

Discussion

The study highlights some important findings regarding the socioeconomic condition and health status of clients with SCD and the delivery of health care services in North Carolina. By using self-reported health data and imputed SES data of 1,189 clients in North Carolina, the study reveals the socioeconomic disparity between urban and rural clients with SCD. The implications of the findings are notable.

Table 6. Regression Results: Utilization of Services Model.

Variables	Mean	Standard Deviation	Coefficient (β)		T value	Significance
Constant	—	—	—		0.791	0.430
Distress	12.08	2.69	−0.293**	β_1	−2.06	0.040
INTF	3.71	3.70	0.002	β_2	0.032	0.975
WMEDICAL	107.1	100.8	−0.032	β_3	−0.50	0.618
Distance	61.85	30.42	−0.201	β_4	0.759	0.627
Location	1.7	0.46	0.377**	β_5	5.93	0.000
Distance_SES	768.65	421.45	0.466*	β_6	1.46	0.144
Dependent						
UTS	0.36	0.376	—		—	—

$R^2 = 0.168$; $F = 8.88$ ($P = 0.000$); n = 270; df. = 269.
* Coefficient signficant at .01 level (2 tailed).
** Coefficient significant at .05 level (2 tailed).

The direct impact of the differences in socioeconomic backgrounds among the young SCD population in urban and rural areas may not be apparent. However, this study shows that they have important implications for health care and delivery of services for clients with SCD who live in such deprived conditions. Research shows that both access to care and care outcomes continue to be affected by such variables as socioeconomic status, race and place of residence (Albrecht, et al., 1998; Cramer, 1987). Generally, distressed population often refers to people in a central city or urban area; however, most of the rural areas in the United States are also seeing signs of increasing distress. Challenges in rural areas have been compounded in recent years by the increasing income and employment disparities that exist between urban and rural settings (Jensen and Tienda, 1989; Summers, 1991; Tolbert and Thomas, 1992; Hague, 1997). People in urban areas generally have access to more if not better public services and health care than the rural counterparts. As suggested from this study, socioeconomic factors do influence clients' access to health care. Persons with SCD who live in condition of distress are not likely to utilize health care, as would be expected. In this case, socioeconomic factors are not necessarily a direct cause of the disease, but a deterrent to improving the quality of life even though services are available. People in high distress situations are likely to lack the social support that is needed to improve their health status (Cassel, 1976; Faresjo, 1992). Indeed, it has been argued that rural minorities are among the most medically understudied and underserved of all population groups in the country (Brathwaite and Taylor, 1992; William, et al., 1994). Notable here is the distance of clinics from clients' actual place of residence. Anecdotal evidence suggests that the farther a clinic is from home, it creates additional burdens for clients, especially those with chronic conditions who must make regular visits to their care providers. Higher rates of utilization of services may indicate a wider market for providers but at the expense of a client's suffering who is already in poor health and also living in poor socioeconomic conditions. The limited availability of medical and health care as well as other systems of support for adult clients need to be addressed, especially community-based health care. These findings should be of particular interest to the state-level SCD program in North Carolina and other states with a large rural population. Enhanced support for all persons with SCD in North Carolina, particularly those in rural areas, is critical.

One limitation of our findings needs to be highlighted. The study uses the client's ZIP code and linked socioeconomic data as a basis for determining CDI score. Such imputed values may not actually reflect a client's real socioeconomic condition; however, such imputations are good proxies of the general socioeconomic characteristics of the area in which a client lives.

Finally, as noted by Tomas Faresjo (1992), in the field of social epidemiological research, there is an increasing *need* for the development of theoretical models and frameworks as support in the analysis of social factors and health. By combining social factors with health, this study indeed is challenging, but one with great promise.

Furthermore, the study utilized a geographic information system, an innovative tool that has helped combine data in creative ways in order to comprehensively conceptualize the problem into one snapshot. Particularly for this study, geographic information systems have allowed the much needed integration of knowledge of social science and health, a challenging exercise in understanding the problems, and better use of information and technology. Indeed, as noted by Croner, et al. (1996), geographic information system databases offer new and powerful opportunities for disease assessment and prevention.

Notes

1. Duke University Medical Center (adults, children and adolescents); the University of North Carolina Medical Center (adults); and East Carolina Medical Center (children and adolescents).
2. All information was gathered for the black population only because SCD in the United States occurs mostly in that population (95% of all cases).

Acknowledgements:

This study was supported in part by the Maternal and Child Health Bureau, US. Department of Health and Human Services (Grant MCI 9040) and the Lister Hill Health Policy Center at the University of Alabama at Birmingham. Do not quote without permission of the authors. Special thanks to the members of the Duke/University of North Carolina Comprehensive Sickle Cell Center, the staff of the four North Carolina sickle cell community-based programs and the state educator counselors who conducted' the client interviews. Thanks to the Biometry Core staff of the Duke/ UNC Comprehensive Sickle Cell Disorder Center for their work on the data templates and management work, to David Redden of the University of Alabama at Birmingham's Comprehensive Cancer Center Biostatistical Core for his critical statistical assistance and to Professor Mahmud Hassan for his insights on the statistical interpretation of health care delivery and services. Special thanks to Jan Hithchcock for her editorial review and suggestions. Most of all, thanks to the individuals with sickle cell disease and their families for allowing us to explore their lives for the benefit of the Sickle Cell Disorder community in North Carolina and the country. For more information, contact Aldilaque Hague, Ph.D., at the University of Alabama at Birmingham, U238, 1530 Third Ave., S., Birmingham, AL 35294-3350.

References:

Abrams, MR, Phillips, G, & Whitworth, E. (1994). Adapting and coping: A look at a sickle cell population over the age of 30-An integral phase of the life long development process. *Journal of Health and Social Policy*, 5, 141-160.

Albrecht, S, Leslie, C, & Michael, M. (1998). Community family and race/ethnic differences in health status in rural areas. *Rural Sociology*, 63, 235-252.

Aldrich, T, Lucy S, & Peggy, W. (1994). Contagious diseases. In T Ricketts, L Savitz, W Gesler, & D Osborne (Eds.), *Geographic methods for health services research* (pp. 277-309). Lanham, MD: University Press of America.

Andersen, RA, McCutheon, R, Aday, LA, Chin, G, & Bell, R. (1983). Exploring dimensions of access to medical care. *Health Services Research*, 18, 50-74.

ArcView GIS. (1992-1999). *Arc View GIS Version 3.11 (Desktop Mapping Software).* Redlands, CA: Environmental Systems Research Institute

Barrett, DH, Wisotzek, LE, Abel, GG, Rouleau, JL, Platt, AF, Pollard, WE, & Eckman, JR. (1988). Assessment of psychosocial functioning of patients with sickle cell disease. *Southern Medical Journal*, 8, 745-750.

Braithwaite, RL, & Taylor, SE. (1992). African-American health: An introduction. In Braithwaite, RL & Taylor, SE (Eds.), *Health Issues in the Black Community*, (pp. 3-5). San Fransisco, CA: Jossey-Bass.

Cassel, J. (1976). The contribution of the social environment to host resistance. *American Journal of Epidemiology*, 104, 107-123.

Charache, S, Lubin, BH, & Reid, CD, (Eds.). (1992). *Management and therapy of sickle cell disease.* U.S. Department of Health and Human Services, Public Health Service, Publication No. 92-2117, Washington D.C.: National Institutes of Health.

Cohn, S, Moorhead, L, Meade, M, & Albert, D. (1994). Contagious diseases. In Ricketts, T, Savitz, L, Gesler, W, & Osborne, D (Eds.), *Geographic methods for health services research* (pp. 241-275). Lanham, MD: University Press of America.

Cramer, JC. (1987). Social factors and infant mortality: Identifying high-risk groups and proximate causes. *Demography,* 24, 299-322.

Croner, CM, Sperling, J, & Broome, FR. (1996). Geographic information systems (GIS): New perspectives in understanding human health and environmental relationships. *Statistics in Medicine,* 15, 1961-1977.

Gil, KM, Abrams, MR, Phillips, & Williams, DA. (1992). Sickle cell disease pain: Predicting health care use and activity at 9-month follow-up. *Journal of Consulting and Clinical Psychology,* 60, 267-273.

Faresjo, T. (1992). Social environment and health-A social epidemiological frame of reference *Scandinavian journal of Primary Health Care,* 10, 105-110.

Hague, A. (1998). Use of geographic information system (GIS) in mapping distressed areas of cities. *Journal of Urban Technology,* 5(3), 47-59.

Hague, A. (1997). *Regional development issues and opportunities: An interpretation of demographic, economic, and transportation related data for Jefferson and Shelby counties, Alabama 1980-90.* Research Publication, Center for Urban Affairs, University of Alabama at Birmingham.

Hicks, JL. (1990). Availability and accessibility of rural health. *Journal of Rural Health,* 6, 485-505.

Jensen, L, Tienda, M. (1989). Nonmetropolitan minority families in the United States: Trends in racial and economic stratification, 1959-1986. *Rural Sociology,* 54, 509-532.

Kinney, TR. (1993). Model Rural Sickle Cell Center In Stern, KS & Davis, JG (Eds.), *Newborn screening for sickle cell disease: Issues and implications,* (pp. 75-84). New York, NY: Cornell University Medical College, The Council of Regional Networks for Genetic Services.

Kramer, ICD, & Nash, KB. (1992). Self-help group models: An ecological conceptualization. In Katz, AH, Hedrick, HL, Isenberg, DH, Thompson, LM, Goodrich, T, & Krutscher, AH (Eds.), *Self-Help: Concepts and Applications* (pp. 144-148). Philadelphia, PA: Charles Press.

Krieger, N. (1992). Overcoming the absence of socioeconomic data in medical records: Validation and interpretation of a census-based methodology. *American Journal of Public Health,* 82, 703-710.

Krieger, N, & Gordon, D. (1999). Use of census-based aggregate variables to proxy for socioeconomic group: Evidence from national samples. *American Journal of Epidemiology,* 150, 892-896.

Nash, KB. (1991). Psychosocial Interference Scale In Nash, KB, *Impact of Self-Help Groups on Adults with Sickle Cell Disease.* Chapel Hill, NC: Psydiosocial Research Division of the Duke Comprehensive Sickle Cell Center, School of Social Work, University of North Carolina.

Nash, KB, & Telfair, J. (1994) Sickle cell disease: A biopsychosocial model. In Livingston, IL, (Ed.), *Handbook of Black American Health: The Mosaic of Conditions, Issues, Policies, and Prospects* (pp. 123-139). Westport, CT: Greenwood.

Parker, AW. (1974). The dimensions of primary care: Blueprint for change In Andreopoulous, S. (Ed.), Primary *Care: Where Medicine Fails,* (pp. 15-76). New York: John Wiley & Sons.

Reid, CD, Charad-te, S, & Lubin, BH, (Eds.). (1994). *Management and Therapy of Sickle Cell Disease,* U.S. Department of Health and Human Services, Public Health Service Publication, No. 94-2117. Washington, DC: National Institutes of Health.

Reif, S, DesHarnais, S, & Bernard, S. (1999). Community perceptions of the effects of rural hospital closure on access to care. *The Journal of* Rural *Health,* 15, 202-209.

Roberts, E. (1997). Neighborhood social environments and the distribution of low birthweight in Chicago. *American Journal of Public Health,* 87; 597-603.

Rooks, Y, & Pack, B. (1983). A profile of sickle cell disease. *Nursing Clinics of North America,* 18, 131.

Saul, C, & Payne N. (1999). How does the prevalence of specific morbidities compare with measures of socio-economic status at small area level? *Journal of Public Health Medicine,* 21, 340-347.

Serjeartt, GR. (1985) *Sickle Cell Disease.* Oxford, U.K.: Oxford University Press.

Summers, GE (1991). Minorities in rural society. *Rural Sociology,* 56, 177-188.

Thompson, R, Gil, K, Abrams, M, & Phillips, G. (1992). Stress, coping and psychological adjustment of adults with sickle cell disease *Journal of Consulting and Clinical Psychology,* 60, 433.

Tolbert, CM, & Thomas, L. (1992). Earnings inequality in the non-metropolitan United States: 1967-1990. *Rural Sociology* 57, 494-511.

U.S. Bureau of the Census. (1990). Summary Tape File 1, 2, 3. Compiled through Census CD 1.1m, GeoLytics Inc., 1996.

Vavasseur, J. (1987). Psychological aspects of chronic disease: Cultural and ethnic implications. *Birth Defects,* 23, 144.

Vichinsky, EP, Hurst, D, & Lubin, BH. (1983). Sickle cell disease: Basic concepts. *Hospital Medicine,* 44(2), 128-158.

Wagner, GM, Vichinsky, EP, Lande, WM, & Pennathur-Das, R. (1989). Sickling syndromes and unstable hemoglobin diseases. In Mentzer, WC & Wagner, GM, (Eds.), *The Hereditary Hemolytic Anemias.* (pp. 145-221). New York, NY: Churchill Livingstone.

Whitworth, E. (1992). MC. *Sickle Cell Syndrome Program: Annual Report FY 91-92.* Raleigh, NC: Division of Maternal and Child Health, North Carolina Department of Environment, Health, and Natural Resources.

Whitworth, E. (1993). *N.C. Sickle Cell Syndrome Program: Annual Report FY 92-93.* Raleigh, NC: Division of Maternal and Child Health, North Carolina Department of Environment, Health, and Natural Resources.

Williams, DR, Risa, L, & Rueben, W. (1994). The concept of health status in America. *Public Health Reports,* 109, 26-41.